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ABSTRACT

This report reviews the development of independent service coordination for people with disabilities in Illinois and offers recommendations in support of free-standing and independent service coordination in the state. First the report defines independent service coordination, then it reviews the policy of the Illinois Planning Council on Developmental Disabilities in support of case management and coordination across agencies since 1989, with emphasis on relevant legislative and executive policy actions. The benefits of independent service coordination are identified, including assuring choices and independence for people and providing a single place to which people can go to receive assistance from the human service system. The current system of independent service coordination agencies is seen to be primarily the result of the Bogard Consent Decree of 1993 which called for comprehensive service coordination reorganization. Recommendations are offered, including: (1) adoption of a state policy supporting free-standing and independent service coordination for everyone seeking assistance from the human service system; (2) utilization of the existing network of independent service coordination agencies as the infrastructure for the system; and (3) designation of an independent state-level entity not involved in service delivery to oversee provision of service coordination in Illinois. An appendix contains an excerpt from a 1988 case coordination project's final report. (DB)

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INDEPENDENT SERVICE COORDINATION:

THE PAST, PRESENT AND FUTURE

IN ILLINOIS

January 16, 1996

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Foreword

Many human services agencies in Illinois are now evaluating the services they provide and how they provide them. As a result of negotiations currently underway in Congress, the federal government could be playing a diminished role in determining how and what services are provided in Illinois. States will have much more flexibility in making administrative decisions that are tailored specifically for each state. This paper provides a rationale for Illinois policy makers to consider the role of independent service coordination as they make decisions about how to change service delivery in Illinois.

The Illinois Planning Council's (IPCDD) support for independent service coordination dates back to 1989 when it adopted a policy promoting independent and free-standing service coordination:

> *".....the Illinois Planning Council on Developmental Disabilities supports the concept of a life-long, local, independent and free-standing system for individual service coordination that is coordinated across state agencies. Independent and free-standing means that the individual service coordination agency provides only service coordination services and has a governing board consisting entirely of non-service providers such as family members, people with developmental disabilities and other non-provider community members." (IPCDD, 1989)*

Additionally, the IPCDD coordinated and published a series of issue papers in February of 1991, "The Common Pursuit - Improving the Quality of Life for Illinois Citizens with Disabilities:Implications for Restructuring the Planning and Management of State Services":

> *"A system of independent, not-for-profit case coordination agencies would be established throughout Illinois to serve people with disabilities. These agencies would receive state funds and be subject to state regulations, but would be governed by independent boards of directors.....Case coordination staff will be able to act solely in the interests of the people they service, without ties to any service providing entity." (IPCDD, 1991)*

The IPCDD Three Year State Plan contains the following goal:

> *"The Planning Council will promote and support the developmental of a consumer-driven state-wide individualized service coordination capability that is life-long, independent, free-standing and ensures a single point of entry into formal systems of services and supports for all persons with disabilities and their families." (IPCDD, 1994)*

The IPCDD thanks Debra Kunz, Sharon Lawson, Richard Bell, Joyce Helander, Betty Ghent, Richard Hemp, Rhonda Best, Tony Paulauski, John Donnelly, Douglas Kane, Steve Deusinger, Barbara Thomas, Dixie Gasparini, Malia Arnett, Raylene McGonigal and Janice Prunier-King for their significant contributions to this white paper.

I. WHAT IS INDEPENDENT SERVICE COORDINATION?

During the years 1987 through 1989, the Illinois Planning Council on Developmental Disabilities (IPCDD) examined service coordination in Illinois in an unpublished report, "An Examination of State Agency Case Management Systems Affecting Persons with Developmental Disabilities". (Morton, 1989) The report detailed case management requirements across all human services agencies and, using that information, defined case coordination:

> *"The purpose of case management services is to increase the accountability of the system, to improve the accessibility of services, to assure the continuity of care and to coordinate the efforts of service providers for the benefit of persons in need of services. Whether the perspective of the agency is to promote the rights of the individual receiving services or to promote the efficient use of limited resources, case management is seen as a means to exercise control over the process of providing services. None-the-less, services are often not available, are difficult to obtain, or are poorly coordinated across various state and local agencies."*

A variety of terms have been used for the kinds of activities described above, i.e., case management, case coordination, service coordination. However, the above characteristics are common to all case management services. This paper uses the term, "service coordination", to refer to activities and responsibilities generally described in the 1989 definition. Additionally it makes a distinction between "independent" service coordination and service coordination provided by agencies which provide other services (multi-service agencies).

The differences between independent service coordination and service coordination provided by multi-service agencies can be explained best through analogy:

> *The Illinois human service delivery system can be compared to a large shopping mall with many stores, large and small, specialty and department. The anchor store of this complex is a Walmart. On entering, the customers are approached by a "greeter" who welcomes them to the store, makes them feel at home, tells them where everything is in the Walmart store and makes sure they have shopping carts. The "greeter" is like the service coordinator within a multi-service providing agency. He/she helps customers while they are customers at Walmart.*
>
> *The independent service coordinator, in contrast, doesn't work for any of the stores in the mall, but works only for the customer. This coordinator knows all the stores in the mall and what they offer, how they treat customers, their strong and weak points. This coordinator can, therefore, make sure people know what choices they have and help them if they have problems or complaints with any store. Customers have confidence in the coordinator because they know he/she doesn't work for any store but*

just for them.

The effective independent coordinator also makes the effort to have a positive relationship with store owners who might be willing to go out of their way for customers with special needs. The independent coordinator can be of great help to store owners by alerting them to problems with their stock and/or staff based on the feedback he/she hears from customers. This provides stores and their parent companies with good solid market research about what customers want and don't want. All stores equally have access to this marketing and quality assurance input and information. This is not possible if the service coordinator is not independent from the stores in the mall. Independence is the indispensable key. (Bell, 1995)

Independent service coordination is: 1) Free-standing (does not provide any other service in addition to coordination activities); and, 2) Independent (is not affiliated financially or organizationally with agencies who provide other services). Service coordination provided by multi-service agencies does not have these two critical characteristics.

II. THE HISTORY OF SERVICE COORDINATION

Service Coordination is Required of All Human Service Agencies. Service coordination has been an element of the human services system for over two decades. The federal Developmental Disabilities Act (P.L. 95-602, as amended) has contained requirements for service coordination since 1978. State law has required service coordination for persons with developmental disabilities since 1983. House Bill 69 requires that service coordination be part of the total service system plan. Additionally, service coordination has been allowable under the state Medicaid plan and required under the Medicaid Home and Community Based Waiver. As a result of the Nursing Home Reform legislation in OBRA - 1987 (P.L. 100-203), Pre-admissions Screening (PAS) Services began in 1989 to determine diagnosis of developmental disability or mental illness and the necessary level of care that a person requires.

Service coordination is also provided under a multitude of federal and state mandates to individuals who use the services of the Department of Alcoholism and Substance Abuse (DASA), the Department of Public Aid (DPA), the Illinois State Board of Education (ISBE),

the Department of Children and Family Services (DCFS), the Department of Rehabilitation Services (DORS), and the Department of Public Health (DPH). With the exception of coordination used by individuals who are members of the Bogard Consent Decree class, service coordination provided and paid for by these agencies are not independent of service provision.

The Emergence of Independent Service Coordination was Gradual. The first Independent Service Coordination Agency for people with developmental disabilities was funded by a grant from the Illinois Planning Council on Developmental Disabilities in 1980. The need to separate the service coordination function from direct service delivery gained momentum during the 1980's.

There is evidence of this momentum in the IPCDD report, "Case Coordination Project: Final Report on Grant Funded Activities". (Morton, 1988) The report summarized numerous events within Illinois and across the nation between the years 1980 and 1989 which exemplify the growing rationale supporting independent service coordination. (see appendix 1, excerpts from, "Case Coordination Project: Final Report on Grant Funded Activities")

Three Recent Important Policy Initiatives Have Supported Independent Service Coordination In Illinois. Since 1990, service providers, advocates and consumers of services have collaborated three times to envision a service system that includes a distinct and separate comprehensive system of service coordination. The preference for such a separate and distinct system has been embodied in three policy papers developed recently in Illinois. The House Bill 69 (Public Act 86-921) Advisory Committee Status Report (HB 69 Advisory Committee, 1990); The Common Pursuit, Improving the Quality of Life for Illinois Citizens with Disabilities: Implications for Restructuring the Planning and Management of State Services (IPCDD, 1991); and, Strategic Planning for Services and Supports in Illinois (Advisory Council for Unified Services/Supports to Illinois Citizens with Developmental Disabilities, 1993).

First, in 1990, the House Bill 69 Advisory Committee, appointed by Governor James Thompson as a result of Public Act 86-921 worked intensively for over a year to establish a set of "Service Principles" to guide policy-makers in making improvements in the Illinois service delivery system. The Committee was representative of advocacy groups, service providing agencies, consumer interests and state agencies. Many of the individuals participating in the Committee continue to be key stakeholders in Illinois today. The Committee then used working subcommittees and focus groups to formulate a series of principles and procedural recommendations regarding service coordination, comprehensive diagnosis and evaluation, and individual program plan development.

> *Regarding service coordination the Committee recommended that the State of Illinois develop a service coordination and advocacy system, including guaranteeing that each person with a developmental disability receiving or requesting services in Illinois have access to service coordination and that such services be available in all areas of the state. Additionally, the Committee said that service coordination should be operated by entities which are independent from agencies who provide services other than service coordination (multi-service agencies); Illinois should integrate current case management services now provided in order to simplify the system for consumers; an Access Services Commission should be created which would distribute funds to service coordination agencies and regulate service coordination; and, emergency service coordination should be implemented guaranteeing access to all persons with developmental disabilities. (HB 69 Advisory Committee, 1990)*

Second, in 1991, as a direct result of work completed by the House Bill 69 Advisory Committee, the Illinois Planning Council convened work groups consisting of over 80 representatives from advocacy groups, provider agencies and state agencies to develop "white papers" on a variety of issues important to improving service delivery to people with developmental disabilities in Illinois. Regarding service coordination, the group envisioned:

> *A comprehensive case coordination system will exist which provides professional assistance in locating and securing needed services and benefits for person with disabilities and their families. This includes coordination and monitoring of those services, for as long as they are needed.*
>
> *A system of independent, not-for-profit case coordination agencies should be established throughout Illinois to serve people with disabilities. These agencies would receive state funds and be subject to state regulations, but would be governed by*

independent boards of directors. Funding would be based on annual estimates of demand, and would ensure realistic caseloads. The agencies would be required to meet state standards for service provision and for staff qualifications. Some agencies of this type exist presently in Illinois, although the scope of their services is limited.

This system will make available to all people with disabilities the specialized assistance necessary to locate and obtain needed services. Case coordination staff will be able to act solely in the interests of the people they serve, without ties to any service providing entity. Services will be available as a person changes service agencies and as transitions are made between service systems.

The system should be administered by a board or commission appointed by the Governor. The commission would provide funding, set policies, establish regulations, and provide leadership for the case coordination agencies. (IPCDD, 1991)

Third, in 1992, Governor Edgar, former Director Jess McDonald (DMHDD) and former Director Phil Bradley (DPA) created an Advisory Council for Unified Services/Supports to develop a plan to enable Illinois to better serve people with developmental disabilities and their families. More than 60 people representing a broad cross-section of persons with developmental disabilities, parents, advocates, service professionals and others participated on the Council. The Committee came to concensus on a series of principles, visions and targeted actions on a full spectrum of issues of importance, including service coordination.

The Committee stated, "individual services coordination must be available to persons with developmental disabilities and their families to assist them in accessing the generic and specialized supports they need or choose throughout their lives" and to "play the key role of personal advocate to help individuals and families obtain the full range of support and services that will assist them in realizing their preferred life-styles."

The Committee further recommended an "accessible network of life-span individual service coordinators to assist families and individuals with developmental disabilities to access and receive the full range of supports they need regardless of governmental agency jurisdiction."

The Committee also addressed how service coordination should be supported by suggesting that Illinois "combine the various funding sources and functions of service coordination, case coordination, and pre-admission screening across all state agencies into one service and support program operating in the community."

Finally, the Committee recognized the importance of shifting to a consumer focused system: "Illinois' system of life-span individual services coordination will clearly focus upon the unique needs, desires, and satisfaction of person with a developmental

disability and their families or guardians." (Advisory Council for Unified Services/Supports, 1992)

Each of these three groups recognized how service coordination that is independent and free from conflict with multi-service agencies would improve many aspects of the human services delivery system, including the ability to "increase the accountability of the system, to improve the accessibility of services, to assure the continuity of care and to coordinate the efforts of service providers for the benefit of persons in need of services".

III. WHY IS INDEPENDENT SERVICE COORDINATION IMPORTANT FOR PEOPLE AND THE STATE OF ILLINOIS?

All people in the nation have the same freedoms, privileges, constitutional/civil rights and responsibilities. They have the right to be free from discrimination, be safe, have the best possible health, be satisfied with their lives and make their own choices. Yet, when individuals find themselves in need of services and supports, they are often inhibited or prevented from exercising those rights. The services they can get are not always the services they want and need to make their lives better. Independent and free-standing service coordination would provide the catalyst for improvements in the entire service delivery system.

Independent Service Coordination will Assure Choices and Independence for People. Multi-service providers find themselves in positions of conflict in writing individual plans and making referrals for their own services.

A young woman preparing to graduate in 1996 from the public school system recently was invited to attend an individual planning meeting, the purpose of which was to assist her in determining how she would be able to meet her personal goals. Her personal objectives are to have a home of her own, a real job in the community and to learn how to drive so she will have the ability to get to her job and enjoy participation in the community as fully as possible. Present at her meeting were school professionals and a representative from one local agency, even though it was clear that the young woman would need supports provided through several adult human services agencies. At her "planning meeting", professionals congratulated her for having plans that were admirable. However, she would have to "work up" to reaching those goals. In the meantime, she may be able to get on a waiting list to live in a group home. If she was successful in getting "into the group home", she would "work at a workshop". She was visibly disappointed, yet no effort was made to plan services that would support her in reaching her goals. This young woman had no one person who could independently assist her in identifying what services were available from a variety of sources and to help her get those services.

Independent service coordination can assist individuals in assessing their needs and in person-centered futures planning which is conflict-free and based solely on individually desired outcomes and help the person seek the services from multiple special and generic providers and sources.

Independent Service Coordination Helps People Find Alternatives to Institutional and/or Segregated Living. For a long time now, many have agreed the current service system in Illinois is overly dependent on segregated "programs" and institutional care. These are the most expensive and restrictive options, yet, in many cases, are the only options available to individuals and their families.

An independent service coordination system can help people move out of costly segregated programs into more integrated and appropriate environments. Independence from residential service providers and state institutions is a crucial element in assuring people know about all of the possible choices.

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Through independent service coordination, people can have flexible and more individualized support and services, and people can access more natural support systems. Currently, services are provided in an inflexible manner where individuals must take a "bundle" of services even when those services do not provide the support they really need. This "take-it-or-leave-it" approach has little to do with assisting people in fulfilling their life goals and is severely criticized by consumers and their advocates.

> *Two brothers and their families recently expressed their desire for the brothers to work in meaningful community jobs where they would receive competitive wages and work with friends and acquaintances. The brothers lived in a group home and worked in a workshop during specific hours as did everyone who lived in the group home. With the assistance of school personnel, the brothers and their families located work in real community jobs but it was clear the brothers would need job coaching supports. One brother's potential job was during the hours he currently worked in the workshop, the other brother's potential job hours were during the evening. Although job coaching supports were made available for the first brother, the second brother could not receive coaching supports because his job occurred in the evening and, moreover, he was not allowed to be in his home during the day (hours he wouldn't be working) since no professional staff were available at those times. The brother's experience is an example of inflexible services and it caused him to lose a long-awaited opportunity for real work. An independent service coordinator would have been able to advocate without conflict for flexibility in the service.*

Independent service coordination can provide independent support by brokering multiple services from multiple providers, enhancing and assuring maximum and flexible choices, assisting in personal futures planning and maintaining and enhancing the quality of personal outcomes for the individual.

Independent Service Coordination can Provide Individual Advocacy for Persons Seeking Services and in Exercising Their Rights and Responsibilities Under Existing Laws. People's rights are often violated. Everyone agrees individuals often need help to know what

their rights are and how to express, assure and protect them. Multi-service providers providing traditional case coordination and advocacy services find themselves in the position of advocating for the rights of individuals over whom they have significant control.

> *A nursing home in Illinois filed guardianship petitions on thirty-two people who were living there and named a guardian to be paid by the nursing home. The nursing home's intent was to prevent those individuals from leaving the home to live in the community. These individuals needed an independent advocate to intervene with the court on their behalf to have the petitions denied and to assure that the individuals could choose where they want to live. This assistance was provided by a current independent service coordinator. Independent service coordinators have also assisted persons in obtaining new guardians when original guardians have unreasonably refused to let them take advantage of opportunities to better their lives or when they have been abused or neglected.*

Independent service coordination can be an advocate for individuals absent any conflict with current providers of services. Advocacy of this nature will assure that the service delivery system is not violating the rights of the individuals it was designed to help.

Independent Service Coordination Can Provide Individuals and Their Families with One Single Place to Go to Receive Assistance from the Human Service Delivery System and Help Individuals and Their Families During Transitions. The myriad of agencies and programs and various eligibility criteria present major barriers to a cost efficient accountable system which meet the needs and desires of the individuals and families who use it. People desperately need conflict-free help in identifying services, establishing eligibility for a number of programs, appropriately assessing their needs and coordinating services from a multitude of sources.

When the mother of a young woman was dissatisfied with the group home in which her daughter was living and the services she was receiving, she attempted to move her daughter to another service provider in an area that was closer to her home. The new provider had already agreed to assist her daughter in finding a job, provide job coaching supports and to help the daughter move into a home of her own, none of which were available with the current provider. The mother was told it would be up to her to assure that funding would be available. When she approached the current provider, she was told the Community Integrated Living Arrangement (CILA) funds which paid for her daughter's services belonged to the old provider who would not make those funds available to the new provider, even though the new provider had promised the services the mother and daughter wanted and needed. Neither local provider was able to help this family. An independent service coordinator would have been able to work with the family to advocate for more individualized and responsive services and to secure funding for the transition between providers.

Accountability and Responsiveness of the Service Delivery System Can be Enhanced Through Independent Service Coordination. This can be done effectively and efficiently by removing conflicts of interest, "unbundling" services and making the individual the focus of service delivery. Independent service coordination can provide a mechanism to determine whether or not the dollars spent every year on services are resulting in customer satisfaction.

The State will be able to determine if the services people want are the services being offered and be more responsive to evolving customer needs and, therefore, more responsive to the tax payers in Illinois. Independent service coordination would provide a mechanism for managing information related to waiting lists and state-wide service needs and provide information to forecast necessary changes in the service delivery system.

A System of Independent and Free-standing Service Coordination can Assist the State in Organizing and Managing Service Delivery Networks. Any reconfiguration of service delivery in Illinois will require an adequate and conflict-free method of connecting among members of evolving networks. Independent service coordination can work effectively

among providers and consumers of services, connecting, clarifying and facilitating efficiency.

Networks must look at how to operate flexibly and creatively at optimal efficiency while maximizing community support. Within the context of a network, independent service coordination can better plan and utilize multiple community resources in a community support model; maximize choice and flexibility of services for the consumer; enhance cost effectiveness; assure quality in services; facilitate entry into the service delivery system; conduct utilization review; interact and coordinate with other systems, including health and other state or federal agencies; provide a conflict-free mechanism for grievances; provide data base management; and, provide conflict-free information for local and state-wide planning.

V. THE EFFECT OF THE BOGARD CONSENT DECREE ON SERVICE COORDINATION

In 1993, the Bogard Consent Decree called for the most comprehensive service coordination reorganization to date in Illinois. Plaintiffs brought this class action under several established Federal Acts, and the Fourteenth Amendment. They alleged that DMHDD, DPA, DPH, DORS, and DOA failed to provide appropriate placements and services to nursing home residents with developmental disabilities and failed to protect them from harm, and discriminated against them based on their disabilities. A significant portion of the decree ordered action regarding service coordination.

The Decree required the State to provide "long term case coordination services" to each Bogard class member to include:

> *Assuring that the class member has adequate and appropriate assessments for the development and implementation of the class member's individualized services plan and placement;*
>
> *Implementing a choice process;*
>
> *Assuring that a written individualized service plan is formulated in accordance with*

applicable law and regulation and the terms of this decree and with the opportunity for input by the class member and his or her guardian, if any;

Assuring the implementation of the individualized service plan;

Advocating for the class member in securing services and exercising rights, choices, and responsibilities available under state and federal law consistent with the case coordinator's professional judgement;

Facilitating the development of natural networks and supports;

Assuring the provision of emergency and crisis intervention services;

Assuring the provision of transportation as necessary for the class member to implement and facilitate the choice process, and to assist in the selection of vocational, developmental training, or day programming services;

Monitoring services and programs provided to class members to determine their effectiveness and to assure that the class member's well-being , health, and safety are protected and that the class member's choices are respected.

To provide the service coordination, the decree ordered the establishment of independent service coordination agencies, located throughout Illinois. The decree also directed steps be taken to assure service coordination agencies are independent of service provision, including: 1) the development of conflict of interest procedures; 2) the requirement that service coordinators have no functions other than service coordination; 3) the requirement that no more than 10% of the independent service coordination board can be comprised of individuals who work for or are on the boards of direct service providers; and, 4) the requirement that independent service coordinators provide no direct services.

As a result of the Bogard Consent Decree, the current system of independent service coordination agencies was put into place. These agencies represent the only independent service coordination entities in Illinois and are representative of every geographical area of Illinois. Even so, the individuals who currently use their services are limited to those people belonging to the Bogard class. This existing network of independent service coordinators offers Illinois an opportunity to build a unified independent system of service coordination

that will make better use of state and local resources, improve service delivery for individuals and families, improve accountability and enhance the coordination of service networks across Illinois.

VI. RECOMMENDATIONS SUPPORTING A SYSTEM OF FREE-STANDING AND INDEPENDENT SERVICE COORDINATION IN ILLINOIS

In spite of the general concensus reached through recent policy development by the House Bill 69 Advisory Committee (1990), the Common Pursuit work groups (1991) and the Advisory Council for Unified Services/Supports (1992), Illinois has not embraced the full philosophy and values associated with independent service coordination. Currently, within DMHDD, discussions are taking place to decide the future role of the network of independent service coordinators. Serious dialogue has occurred which could reduce the number and diminish the role of independent service coordinators even before Illinois has fully operationalized the system.

The purpose of this paper is to provide a basis for Illinois leaders to adopt free-standing and independent service coordination as a key element in any reconfiguration of the human service delivery system. Regardless of how state government is reorganized, independent service coordination can play a key role from the perspective of the customer and state government alike. Since the early 1980's, the necessity of independent service coordination to overcome problems that are inherent in the delivery of human services has become more and more apparent. These problems include: 1) lack of customer satisfaction; 2) inefficient utilization of resources; 3) lack of coordination between local special and generic service providers; 4) lack of real accountability; and, 5) inflexibility and lack of responsiveness in the service delivery system. All of these issues are eminent in discussions regarding the reorganization in the service delivery system and each could be addressed through the establishment of a comprehensive service coordination system which is free-standing and independent of service provision. The following recommendations are given in the spirit of cooperation in solving problems apparent in the service delivery system and, most

importantly, assuring the individuals and families who find themselves in need of human services can receive services which truly improve the quality of their lives as defined by them.

The State of Illinois should adopt a policy regarding free-standing and independent service coordination accessible to every person/family who seeks assistance from the human service system, regardless of how that system is reconfigured.

The State of Illinois should utilize the existing network of independent service coordination agencies as the infrastructure for the system.

The State of Illinois should designate an independent state-level entity which is not involved in service delivery or paying for direct services to consumers to oversee the provision of service coordination in Illinois.

Consumers, families and advocates should have majority representation on the state-wide entity and on the local boards of the independent service coordinators.

Initially, the State should identify all state and federal sources of funding which support service coordination to provide a basis for adequately funding independent service coordination in Illinois.

The state-level entity should work with independent service coordinators, consumers, families and advocates to develop state-wide standards for independent service coordination services.

The State should provide resources for a program of continuing education for independent service coordinators which would be configured by the state-level entity working in concert with consumers, families and independent service coordinating agencies.

The State should move to a more accountable system in which the customers of services control the dollars and the dollars follow individuals and, therefore, positively influence the flexibility of services and the responsiveness to customer need.

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Appendix 1

Excerpt From

Case Coordination Project: Final Report on Grant Activities

Momentum Toward Independent Case Coordination: Recent Events

Both within Illinois and nationally, there has been a continued momentum toward establishment of independent case coordination services. This momentum is the product of separate events which have the cumulative effect of demonstrating that the need for independent case coordination is being felt by more people in various organizations and service systems. The following quotations express the rationale for independent case coordination from a variety of perspectives.

A. Events Within Illinois.

1. ARC/Illinois, Executive Director's Committee on Developmental Training

This committee's charge was to make recommendations to DMHDD and DPA regarding changes in the Developmental Training system, including general recommendations about Medicaid-funded services. The committee's recommendations included the following:

> Secondly, the role of independent case coordination services should be given a high priority in restructuring Illinois' Medicaid services for the following reasons:
>
> 1. Independent case coordination eliminates real or perceived conflict of interest issues currently attributed to service agencies which provide both case coordination and other services (day, vocational, residential, respite, etc.).
>
> 2. DMHDD and Public Aid will inevitably require validation of client service needs and program recommendations independent from the agency providing those services. Community based agencies specializing in case coordination for persons with MR/DD were considered the preferred model by committee members rather than state agency personnel who may or may not have MR/DD expertise and knowledge of local service alternatives. (p.5)

2. Taylor Institute Developmental Training Study

The purpose of this project was to study developmental training services and make recommendations for service system changes which would result in improved services. These recommendations included the following:

Case coordination is essential for the provision of appropriate client placement, active treatment services, and optimum client independence, productivity and integration into the community. Persons with developmental disabilities receive services from multiple agencies and coordination and continuity of these related services is critical, particularly during transition periods such as childhood to adulthood, school to work, and home to residential environment. The provision of case coordination services would promote the concept of appropriate placement, facilitate implementation of services/programs based on client need, and increase efficiency in service delivery by assuring the utilization of less restrictive, and perhaps, less costly services.

This project has shown that individual provider agencies are not well-suited to provide case coordination between programs and service environments. For this reason, it is strongly recommended that Independent Case Coordination Agencies be developed/expanded to assume responsibility for DT client assessment, placement, development of a single, integrated IHP for each client, and evaluation and monitoring of active treatment services and needed level of care.

3. Task Force on Mental Health Needs of Persons with Developmental Disabilities in Champaign County

A Task Force was established to examine the mental health needs of persons with developmental disabilities in Champaign county, including service system variables that affected how those needs would be met. The Task Force recommendations included:

Establish an independent case management agency that can advocate for clients with no conflict of interest.

B. Events in Other States.

1. Oklahoma: Homeward Bound vs. Hissom Memorial Center.

In July, 1987 Judge James Ellison issued an order to close Hissom Memorial Center, a state facility in Oklahoma. In addition, the Judge ordered the state to develop a plan for his approval regarding a system of community services which included the following statement:

> Case management (independent of service provider agencies) will be provided to insure access to and coordination of supports and services, including participation in education services.

The court order further states:

> An active, resourceful and independent Case Manger is the single most important component of the system. Case Managers must be independent so that they may be free to advocate for the needs of the individual with mental retardation.

2. Task Force on Technology-Dependent Children

This Task Force was established by Congress in order to study the needs of children with special health care needs who are dependent on ventilators and other techonology for survival. The Task Force report makes the following statement and recommendation:

> The single most important aspect of appropriate care is case management. Deliberations by the Task Force continually returned to the necessity for a family-centered, community-based coordinating process if appropriate care is to be assured for technology-dependent children. Where feasible, states should be encouraged to provide this case management service through a public or private agency having no financial interest (either as a provider or payer) in the coordinated service.

3. Iowa: ARC/Iowa Case Management Position Statement.

The developmental disabilities service system in Iowa has been undergoing major changes in recent years, including the passage of a Bill of Rights by the legislature in 1985. ARC/Iowa has issued a position paper on a new, regional service system, which has specific case management recommendations and policy statements, including:

> A system of case management is the most critical component to assuring service delivery which is person-centered and productive for its recipients. It must be structured to assure organizational independence, as well as services, support and advocacy in direct response to the needs of consumers....the Case Manager coordinates prescribed functions and is the primary professional designated to insure service provision.

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> An active, qualified and independent case manager is the single most important component of a case management system. They are the designated professionals responsible for assuring identification and assessment of the needs of an individual, as well as coordinating and monitoring needed services through an interdisciplinary team. In order to be free to advocate for the needs of the individual, the case manager must be independent yet accountable.

4. New Jersey: Governor's Task Force on Services for Disabled Persons.

The Governor's Task Force on Services for Disabled Persons was convened to study the overall system of state services for all persons with disabilities, and made numerous specific recommendations for state officials, including the following on case management:

> A case manager should be neutrally positioned vis-a-vis the various providers from whom continuing services may be purchased by or on behalf of the client/consumer and should not be employed by or have any other direct interest in the particular agencies from whom services are likely to be purchased.

5. National Association of Developmental Disabilities Councils.

NADDC has an ongoing case management policy committee which addresses issues related to case management. In 1987 the committee recommended, and the NADDC adopted, the following statement on independence of case management:

> Case managers must be given sufficient autonomy and authority to, at the direction of the individual with developmental disabilities and his or her family and in consultation with other professionals, determine and coordinate services needed from multiple public and private agencies and resources. Therefore, the NADDC supports the concept of independence of interagency case management systems from the traditional service delivery system.

C. Summary

The statements quoted above indicate that the need for case coordinators to be independent from the provision of ongoing,

direct sevices is being appreciated in different states for similar reasons. There are two basic themes used to argue for independent case management services: the need to avoid conflicts of interest, and the need to provide unbiased assistance to persons seeking to enter the service system. In the first instance, experience has shown that case management functions are best performed when conflicts are eliminated, reduced or controlled. In the second case, the need for independence is seen from the perspective of the individual, and is phrased in terms of the individual's right to services based on an individualized plan of care. In order to exercise this right, the individual often requires the unbiased assistance of an independent case coordinator. From either perspective, these views provide support for the concept of making a transition to an independent case coordination system.